

DISCUSSION PAPER

forced to the margins ... again

Peter Canavan, HIV Living Program Coordinator and
John Rule, Deputy Director

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FORCED TO THE MARGINS¹ . . . AGAIN

INTRODUCTION

This paper was prepared after a special session at the NAPWA General Meeting April 2007² where NAPWA members discussed their response to concerns over sensationalist media attention surrounding recent HIV transmission cases. Members had requested that NAPWA give attention to the context in which HIV criminalisation issues are dominating media discourse and in which public health frameworks seem to be placed in the background. Representatives had reported their own constituents were in contact with them expressing their concerns about the current environment. With recent media reports using language not seen since the late eighties (e.g., 'innocent victims' and 'AIDS carriers') members attending the national meeting were trying to find their own position for action, within what seemed like, quite inappropriate and misleading media coverage. The session explored the effects on the lives, freedoms and socialities³ of HIV positive people.

NAPWA membership forums and special sessions are one important mechanism to canvass the views and opinions of the NAPWA membership on national issues of significance and concern. They provide a safe and confidential space for representatives to share their views and concerns and provide member feedback to NAPWA for national awareness and policy response.

Positive advocates and representatives from around Australia were asked to respond to two questions:

- What are you hearing – now – as the major concerns of the constituents you represent?
- What can be done to support you and your organisation in responding to this?

In an environment in which policy is meant to be developed through partnership and dialogue (within the context of a 5th National Strategy) the recording and reporting of how a population of HIV positive Australians are experiencing this moment is necessary. The following were the areas of major concern reported to NAPWA.

FEAR OF DISCLOSURE⁴: IN HEALTH, RESEARCH AND SOCIAL SERVICE ENVIRONMENTS

In the current environment there are concerns about maintaining levels of privacy and confidentiality which will enable positive people to have confidence that supportive environments will be maintained. The question of 'who can I trust'? [with the information about HIV status and sexual practices] is still a concern. Positive people note they are encouraged to disclose information about their sexual practices in research and clinical environments. Concern is being expressed, following on from recent cases, that the confidentiality of information and records cannot be guaranteed. Positive people note that they also, now, need to disclose their status in wider health, welfare and social service networks in order to access mainstreamed programs. There has also been some concern expressed about electronic health records⁵. In the current climate when mainstream media representation has been about a particularly small group of people in the context of legal actions, positive people are worried about being stereotyped. The fear of disclosure in health, research and social service areas⁶ has also been noted in Indigenous communities.

FEAR OF DISCLOSURE: IN PERSONAL, SOCIAL AND SEXUAL NETWORKS

Research data, including *Futures* and *Positive Health* could be 'mined' further to get a clearer picture of the incidence of disclosure and its effects on positive people lives. Focus group discussions⁷ and campaigns such as those conducted by PLWHA NSW highlight the complicated nature of disclosure in social and sexual contexts.

Any number of quotes could be drawn out, describing the negative consequences experienced by positive people, when they provide information about their HIV status (as required by the law in NSW, for example). Sexual negotiation and disclosure remains a key challenge for people living with HIV/AIDS⁸.

Women with children have reported that disclosure in social and family contexts has become more fraught in recent years. Men living heterosexually with HIV have also noted that they have been forced into a position of 'silence' around their HIV status in social contexts. 'Sero-silence', 'secrecy', 'concealment' and 'dissociated lives' are recorded as part of the experience of men and women living heterosexually with HIV⁹.

INCREASED LEGAL AND SOCIAL BURDENS

Legal burdens are clear as each state and territory has its own public health laws in relation to HIV transmission and some states and territories have criminal offences to cover the intentional transmission of HIV to another person. The extent to which these laws are understood by the Australian population generally (and in fact the HIV positive population) is less clear. There have been attempts through community education programs and the distribution of literature to provide clarity around these legal responsibilities. However, in the current climate where new Australian Commonwealth Reviews are being commissioned and news is coming from countries like the UK¹⁰ where public health laws in relation to HIV/AIDS are also being reviewed (with significant mooted changes), positive people are speaking about increased legal burdens of responsibility.

Positive people recognise that there have always been a set of social responsibilities (or burdens) which come with a positive diagnosis. Many have responded to this through engagement in HIV advocacy and prevention education work, through positive speakers bureaus, for example, since the start of the epidemic. However, there is a different dynamic now occurring in the social world of positive people. This is a dynamic in which positive people are being positioned as being solely¹¹ responsible for all aspects of their social world.

This extends to a feeling of responsibility also for developing a network of services and support structures – it might be worth asking in the context of the re-defining of HIV as a chronic manageable illness whether any other chronic illness groups are held to be responsible for the development of the health and social service infrastructure which they need to access. There are possibly two ways of reading this, the first reading is that it is good to be so actively engaged in shaping service provision and better services will be the result, another reading is that, the demanding advocacy work can be an additional burden when one is already 'managing an illness'.

Perhaps positive people are identifying a trend that has been occurring in Western liberal democracies where marginalised constituents and communities are being held responsible for their own self-management and punished through the withdrawal of state service provision if they do not comply¹² with other legally (or socially) punishable codes of behaviour.

Apart from these legal and social burdens positive people have identified other sets of burdens, associated with managing HIV disease which are not understood and need to be articulated¹³.

THE BURDEN OF HIV IS BEING INDIVIDUALISED

Researchers have identified that the experience of HIV is being taken out of a collective experience and placed, either within the 'clinical space', or managed by individuals in a way that does not allow any longer for a collective reading of HIV positive experience. In this context plwha who speak of '*fear of being quarantined*', '*lack of trust in health workers*', '*concern about disclosing at work*', '*lack of trust in organisations in maintaining confidentiality despite stated policy*', '*feeling that the attitudes are represented in the gay press as well as the general press*', '*being labelled as a carrier*', '*being stereotyped*' and '*being put back in the closet*' should be of grave concern.

If the experience of HIV is being individualised, as suggested by the research, and, if individuals no longer have a social space in which to share, with others, some of their concerns, then the question arises of what an individual who is having these thoughts and experiences does? The NAPWA socialities workshop was a chance for advocates and representative throughout Australia to talk in a safe space about their concerns – but what opportunity is there for any isolated plwha who are not linked into community and social support mechanisms to reflect on their 'individualised' experience? In the absence of safe environments in which to talk, and in the absence of networks which can provide some reflection and validation of fears where they exist – and then provide information where it is needed (if those fears are unfounded) – what assistance can be provided to keep those whose experience is individualised supported so that they don't live in fear, so that they do have confidence in the health and social service systems, so that they can practice self care, and practice that in a way that will include care of others?

THE CURRENT ENVIRONMENT

Two principle driving concerns influencing the current environment are:

- The very public and sensationalist media discourses over a small number of exceptional cases of HIV transmission.
- A worrying move to position public health frameworks and responsibilities to the background, whilst debate rages about whether or not – and to what extent – it is appropriate to expose HIV positive people to more intensive health management and criminal prosecution options, possibly even outside of well established public health mechanisms, in favour of other intensive management strategies, including mental health orders, or guardianship responses.

It is now apparent that personal freedoms are being questioned, through moves to enhance surveillance and control over the sexual lives and behaviour of positive people, with the potential to further shift the legal and social responsibility for social and sexual contacts involving positive people.

Some of the ways that this is affecting HIV positive socialities is:

- Fear over disclosure of status in social and sexual contexts
- Patient confidentiality concerns affecting access to clinical monitoring, management and support
- Confidentiality concerns affecting research participation
- Confidentiality concerns affecting confidence in public health systems and management
- A return to the early days of the HIV epidemic in Australia with HIV pushed to the margins
- Changes in general public perceptions, including stereotyping, moral judgements and increasing HIV related stigma

- A lack of leadership and responsible commentary from the government and the bureaucracy
- A breakdown of processes and communications which underpin the current structures supporting Australia's HIV response
- In the context of an increasing focus on clinical management and individualised experiences of HIV, concern exists over where an HIV positive person can find supportive and safe peer environments to assist in self care and the care of others.
- The renewed marginalising of HIV together with individualised experience of HIV by positive people is bringing into question concerns over who has responsibility for developing appropriate and supportive environments to assist with the human and social dimensions of the health and wellbeing of positive people. If public health will not create these supports, then has this responsibility fallen to HIV positive people to do this for themselves, yet again? Why would this be so? Why is public health not seemingly able or interested in supporting positive people to take an active role in the prevention of HIV transmission through support mechanisms, rather than through problematising, managing and marginalising?

WHAT IS NEEDED NOW?

Awareness and action is needed to ensure that responses from this current environment do not further pathologise and stigmatise HIV – not only the individual with HIV but the ways that all positive people are viewed through the lens of diminishing social capital, fear, blame and onerous public health responsibilities, increased surveillance or control measures.

WHAT CAN NAPWA DO TO ASSIST?

One of the most significant things that NAPWA could do to assist HIV positive people and communities is to revitalise efforts aimed at:

- Dispelling emerging myths and untruths about social responsibility deficits of HIV positive people, especially in highlighting the responsible behaviour of the overwhelming majority of plwhas in both social and sexual contexts.
- Making visible the powerful and participatory actions of HIV positive communities and specific populations in supporting, developing and underpinning the national response to the HIV epidemic.
- Highlighting the expertise and experience that HIV positive people have developed and offer in collaborative partnership in contributing to the national HIV response in Australia.
- Continuing to represent the complexity of experience of living with HIV.
- Continuing to make visible the role of positive people in a prevention ethic and provide information and support for HIV positive people or 'positive in prevention' efforts.

SPECIFIC RESPONSES

1. LEGAL AND POLICY FRAMEWORKS:

NAPWA has a continuing role to play in ensuring that Commonwealth and state policies, guidelines and processes for the control and management of people with HIV who endanger others or are accused of endangering others are fair and reasonable. Further, NAPWA would seek to ensure:

- That there are clear definitions about what is 'deliberate', 'endangerment' or 'recklessness'.
- That all positive people have access to the fullest information about their legal responsibilities and recourse to consistent, reliable information on the law in relation to disclosure of HIV status and processes governing intentional transmission of HIV.
- That there is acknowledgement of increased stigma, ostracism and potential discrimination when management and control processes operate in a climate of fear, blame and uncertainty.
- That there is advocacy for additional clinical supports, counseling and peer support initiatives to encourage clinical and social self-care and care of others.

2. DISCLOSURE AND SUPPORTING POSITIVE PEOPLE:

Current legal and social environments are impacting (negatively) on the lives of positive people. Disclosure in sexual contexts often occurs with fear and uncertainty. NAPWA has a role to play in assisting positive people in this time, but also a role in educating others in the national partnership to improve current understandings, practice and health promotion supports to reduce the negative impacts being experienced by positive people.

- It is clear that with no uniform legislation governing disclosure and individual state jurisdictional differences and obligations, that positive people need additional assistance to support individual behavior and to remain informed around legal requirements around the nation.
- In this context and in consideration of what constitutes best practice approaches to disclosure laws, it is important to undertake an assessment of the effects of disclosure frameworks upon the lives of positive people before decisions are made regarding national frameworks.

SUMMARY

This paper has used as its starting point the input of HIV positive representatives and advocates from around Australia. Fear of the consequence of disclosure of HIV status in health, research and social service environments is real. Fears around disclosure in personal, social and sexual networks should not be downplayed. NAPWA members have reported these fears. The sense of increased legal and social burdens has also been noted, and, as well, a sense that there are no peer and support forums for talking through difficulties encountered. The burden is being individualised but there is a diminished collective space in which to explore the consequences of that. The NAPWA socialities workshop was an attempt to surface some of the concerns at this current moment and this paper is an attempt to inform and engage with others about these concerns.

FOOTNOTES

1. Altman argues in *The Monthly*, December 2006-January 2007 that in a global picture attention on HIV/AIDS has largely vanished from public consciousness (forced to the margins), this discussion paper suggests that there has been, recently in Australia, a bringing to consciousness of HIV/AIDS in the national media in a way that is negatively impacting on the lives of positive people. The marginalisation that is occurring is not marginalisation in the sense of forgotten, but marginalisation in the sense of new stereotypes being circulated; stereotypes which are having the effect of positive people becoming unsure of a guarantee of social and community support structures, as has been available in the past.
2. It is worth noting that on the day of the workshop national newspapers contained headline articles in which the Prime Minister of Australia had commented on his beliefs about migration to Australia of people who are HIV positive.
3. By using the notion of 'positive socialities' the session focused on the ways in which people living with HIV/AIDS interact, feel and negotiate the social spaces in which they live and work.
4. *HIV futures V* records that 51.8% of survey respondents had their HIV status disclosed to another person when they did not want it to be (24.9% in the last two years). This figure also includes unwanted disclosure by friends, family and other positive people but still includes startling figures of unwanted disclosure occurring in the workplace of 15.5% (in the last two years) and within health care settings 9.7% (in the last two years).
5. See 'Health Records Online', Abigail Groves *HIV Australia, Vol. 5 No. 3*
6. Bonar M, Greville HS, Thompson SC (2004) *Just getting'on with my life without thinkin' about it: The experiences of Aboriginal people in Western Australia who are HIV positive*, Department of Health, Perth, Western Australia.
7. See PLWHA NSW *Fact Sheet on Disclosure* available and also TALKABOUT Issue #138 May 2005 'disclosure . . . stepping out from the shadows'
8. See also *Risky Business*, David Menadue. *Positive Living* 2003 and also Brent Allan, William Leonard *Asserting a Positive Role: HIV-Positive People in Prevention*, *New Directions for Adult and Continuing Education* Number 105, Spring 2005 pp 55-63
9. See Asha Persson, David Barton and Wendy Richards, *Men and Women Living Heterosexually with HIV*, Straightpoz Study, Vol. 1, NCHSR Monograph 2, 2006
10. "A Department of Health consultation paper that sets out the English Government's proposals for changes to the Public Health (Control of Disease) Act 1984 appears to considerably widen the potential use of coercive powers of justices of the peace (JPs) or magistrates and may even criminalise HIV-positive individuals who have unprotected sex, according to Dr Matthew Weait, an expert on HIV and the law." *Aids Map News*, Edwin J. Bernard, Wednesday, May 30, 2007
11. See discussion paper by Ross Duffin (2004) which includes sections about the 'responsibility' that positive people feel for the education and prevention of HIV infection in others.
12. See Nicolas Rose, 1999, *Powers of Freedom: Reframing Political Thought* especially pp. 167-197
13. See Peter Canavan, 2007 *Transitions*, a report prepared for NAPWA on the changing needs of plwha

